

## Work Group Recommendations and Meeting Notes

**Outcome 1: Families of children with special health care needs will participate in decision making at all levels and will be satisfied with the services they receive.**

<b>Problem Statement</b>
Michigan enjoys and benefits from existing partnerships (families, hospitals, CSHCS, AAP, multiple health systems, etc.) The partners have models and tools to advance family-centered partners and awareness. The recently established National Collaborative holds promise for finding the evidence and highlighting disparities in patient and family-centered care. In order to continue to advance progress for attaining the federal 2010 goal: 1) We must define standards for: a. Communicating program benefits and how to access them. b. Engaging families as partners. c. Funding to support family involvement. 2) Build coalitions among stakeholders regionally and statewide. Assure that family partnerships are equally available and supported for families, including families that are culturally, linguistically, and socio-economically diverse.

<b>Recommendations</b>
<b>Priority Recommendations presented to large group</b>
Collaborate with partners and build coalitions to assure that all families have full access to consistent and complete information on program benefits, information on the benefits of family partnership; conduct outreach to fathers, grandparents, youth and diverse populations, improve shared awareness of benefits of partnering organizations, develop, translate, and communicate information in multiple formats, languages, and literacy levels Sub priority: Send letters to families with infants on the birth defect registry (18 votes)
New regional structures are required to have family advisories that will dev guidance to prepare, recruit and engage families to become advisors. Composition of family advisory structure will be reflective of community served and inclusive of youth. Each region will have a face-to-face family liaison. Provide minimal standards for financial support for family participation.
Assure accountability of local efforts to achieve collaboration, partnership, and outreach. Use surveys and focus groups to measure and improve satisfaction levels. Require annual reporting on performance towards achieving criteria/objectives articulated in the federal goal
Implement statewide, regional, and local family leadership training

### **Strengths and Opportunities**

- Family-centered committee work efforts at children's hospitals
- Family Voices connecting
- Good models for mothers and siblings can include fathers
- Supported well by CSHCS for conferences
- Families included at different levels
- Have data and evidence based on information to show family participation results in better services—develop a press kit
- A lot in existence regarding family centered practice how to present and share
- Inroad with Medicaid Policy

- Genetics
- Mechanism in place to outreach
- Local contracts with individuals who have/had special need and can talk with new parent to offer them a glimpse of what is possible
- Develop linkages to local CIL's
- Mi AAP—important champions Physician partners
- Compassionate—caring staff, parents are and/or affiliated with families CYSHCN
- F2FHIEC going statewide can fit into regional system—provide infrastructure—having family liaisons to connect with locals
- Doc site—include family child information, web based, family access
- Transition work—including youth in family centered discussions

### **Themes**

1. Education Activities
2. Partners
3. Data to build upon
4. Models and Tools
5. Summit

### **Weaknesses and Threats**

- Services dependent on where you live
- Variability at local level to include families
- Lack of standard set for delivering family centered care, and informing families
- Varying buy-in of health care providers (loss of control)
- Public Health Code hasn't been revised—redefined terms—can create a new situation of having to examine entire code not just CSHCS
- Definition of “family”
- Not allowing for family choice—need to allow for individual family—system cannot impose
- Limited funding to support family centered care
- Lack of coalition to help implement changes statewide—vehicle for working on issues
- Connection to disability specific organizations
- Other state agencies that serve CYSHCN that have the same culture (identify link be part of coalition)
- Variability of “communication” with other programs outreach for family centeredness
- Need to update existing families of new information and policies
- Culture—socioeconomic, language diversity
- Lack of research—splitting data so we know what we are working with

### **Brainstorming Ideas**

- All families across the state should have full participation and access to consistent and complete information
- Increase awareness of website
- Develop, translate, and communicate information in different formats, languages, and literacy levels
- Share information among partners (about multiple level or participation to promote)
- Use surveys and focus groups to measure and improve satisfaction levels
- Require annual reporting on performance towards achieve criteria/objectives

articulated in federal goal

### **Parking Lot**

- Varying levels of family participation
- Need for parent leadership program special education
- Community-based system of care
- Alternative funding infrastructure changes to shape services

**Outcome 2: All children with special health care needs will receive coordinated, ongoing, comprehensive care within a medical home.**

### **Problem Statement**

Michigan acknowledges national development of patient and family-centered medical home definitions in addition to various demonstration projects within the state. Michigan also has multiple programs and resources concerned with meeting the needs of CYSCHN and their families. However, there is no common statewide working definition of family-centered medical home for CYSCHN that includes specific operational criteria; nor has there been sufficient collaboration among those developing other medical home models. Increased collaboration and redirection of funding is needed to develop and support a regionalized system of care that provides a medical home for all CYSCHN.

### **Recommendations**

#### **Priority Recommendations presented to large group**

Develop consensus definition for CYSCHN family-centered medical home and all subsets of medical home such as care coordination in Michigan and method to operationalize that fully involves family representation in each group and process throughout start to finish

Include full integration of all existing programs and other organizations (including community based groups) into the medical home planning and implementation process from start to finish

Address the funding and reimbursement issues allowing for multiple strategies

Develop mechanisms to educate the public, consumers, and train professionals (Training Programs, Medical community process, DME, Academic detailing (get staff and doctor) Colleges of Nursing)

### **Strengths and Opportunities**

- MI has chronic disease clinics
- Multidisciplinary
- Telemedicine (how broadly is it used?)
- Regional Health Information exchanges
- Subspecialists in centers
- Residency programs so can train
- Should learn/collaborate with other program
- NCQA available for certification of MH
- Able to set criteria and not have to follow others
- LHDs can assist whether primary or specialty care—can fill gaps (and other entries)(required vs. what can be done)(staff who care with knowledge)
- Chance to look at best practices from other areas including international successful models in place and chance to review Grand Valley nursing project starting
- Momentum and ground swell occurring now and can build on

- BCBS giving money for practice transformation and money stay once transformed
- High interest in SP today
- National intolerance from broken health care system
- Experience with CC
- Website to find doc could be adapted to MI to make more accessible
- MICR
- Administrative support
- Coordinated funding streams
- Live “bodies” that answer the phone
- Local Agencies—committed to serve
- Agency collaboration
- Family Guide/Family Preparedness
- Dedicated Staff to LHD
- Provider network that remains in place—wont leave the families
- Plethora of services available
- Can use other programs/together/collaborate
- Point of entry: Multiple ways into program, medical from hospital, family mailed application, completed at hospital
- Parents advocate for the program (word of mouth networks)
- Diagnostics
- Database to use for variety of purposes: MICR, Oracle, Claims data
- CM/CC available to families
- Human resources
- Technology Services

#### **Weaknesses and Threats**

- Multiple groups developing own version of MH
- Was to be standardization training didn’t happen
- Provider community needs to be up front about label so know what to do—what path—A comprehensive plan right away
- Process at hospital that will start correct process
- Need for neuro/psych evaluation
- Need electronic medical record
- Care plans written through other programs Doc not part of or aware of and can duplicate
- Money, Training, Education, Promotion
- Exchange of communication among all participants
- Docs don’t have time to participate
- Too long a wait for reports, requests, slow turn around
- Later events often leave family on own to find help
- Need local services including for CC
- Concern of accepting money rather than based on quality could leave pediatric approach by wayside with only measurable results
- Infrastructure; money we don’t have
- Need flexibility of who we include re: providers
- CSHCS limited to specific medical conditions and needs to be broader spectrum
- Need specific criteria that allows certification
- Wide variety of geography need to address regionally
- Do not have all players engaged
- Improve telemedicine section and expand knowledge base

- Lack of awareness of entry point (enrolled via hospital)
- Inability to determine if a service has been provided
- Transportation
- Fear: Loss of funds, loss of control, loss of client base
- Lack of referrals from hospitals/provider networks
- Too many forms or auth processes
- Distrust of government/Big brother in control
- Lack of understanding knowledge of what is available to assist them
- ↓ population ↓ economy
- Duplication of paperwork/effort
- Lack of collaboration PCP vs. Specialist—who is in charge?
- Electronic information sharing (privacy and security)(opportunity to increase)
- Lack of participation of private foundations
- Misinformation on financial requirements to participate in CSHCS
- No single source of info/system or person
- Lack of understanding of how parts can work together
- Maze is growing while funding declines
- Limited availability, 8am-5pm M-F
- Stigma attached to program/welfare?/family able to provide for family
- Lack of respite to support families

### **Brainstorming Ideas**

- Full integration of all existing programs (AAFP, BCPGI, MPCC)
- Broaden stakeholder group
- Actively participate with Primary Care Coalition
- Encourage parental involvement
- Regionalize “In a perfect world” process with parents
- Keep Local Health Departments involved
- Form task force with appropriate representatives to hammer out working definition leading to certification and operationalization
- Explore barriers and solutions for electronic medical records
- Create process for inclusion of non-pediatric providers
- Create process similar to IFSP including family as partner in development per individual
- Define infrastructure of what is included in MH model
- Integrate MH training into (Residency program, Nursing, Health Professionals)
- Define who is care coordinator into definition and each plan of care
- Review historical experience and requirements MI and other states
- Allow for flexibility within model due to regional and other differences
- Create evidence-based definition
- Need flexibility and accountability for argument made from parent perspective so have record
- Parent and coordinator advocacy respected
- Coordinator with dental home activities
- MICR- Expand- vehicle to share medical information
- Development of reimbursement mechanism
- Development of funding mechanism
- Primary care added to CSHCS authorization per child
- Determine how much to cover of primary care

## Questions

1. Definition of Medical Home
2. Definition of Care Coordinator
3. Primary vs. Specialist
4. Does everyone have resources to do this?
5. How to educate residence to be prepared
6. When do you need a medical home?

## Issue Brief - Recommendations

- Needs reference to broaden base such as Primary Care, Family practice, ect...
- Definition need to clean about detail expectations

**Outcome 3: All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.**

### Problem Statement

Although Michigan has one of the one of the lowest rates of uninsured children in the country and a comprehensive CSHCS medical health care program, thousands of children still remain uninsured due to the following barriers:

- 1) Inadequate education and awareness of the program.
- 2) Insufficient identification of eligible children.

### Recommendations

#### Priority Recommendations presented to large group

- Letters to Birth Defect Registry families. (integrated into family participation priority)
- Pursue the Medicaid buy-in option available for children with special health care needs through the federal Family Opportunity Act (families with incomes up to 300% of poverty could buy full Medicaid coverage).
- Improve communication, collaboration, and education to all stakeholders between public/private agencies, professional organizations (AMA, MDA, MAPD, etc.)
- Operate as regions; improve connections between regional hospitals and local health departments and other community agencies.
- Insurance premium payment program: expand/improve awareness and increase enrollment.

## Strengths and Opportunities

- COBRA as insurance premium program
- CSHCS coverage
- Outreach
- Legislative support
- Local health departments
- Regional centers
- Partners
- Good financing
- Low rate of uninsured children
- High rate of employee-based insurance
- Low premium (CSHCS payment agreement fee)
- Monthly payments

- Peace of mind
- Educate congress
- Interagency infrastructure
- Take care of kids (right thing)
- Michigan Cleft Network
- Link on internet through non-profits
- Ongoing discussion
- Strategic planning
- Stakeholders, multiple
- Involve families consistently
- Staff
- Seminars – family to family education
- Informative, helpful, problem-solving Staff
- Powerful Advisory Committee
- Supplemental to insurance coverage
- Education
- Family/Provider Available Services
- Mentoring/Support
- Webpage Instruct

#### **Weaknesses and Threats**

- Medicaid public program – stigma
- Not informed about available program
- Funding limits, economy
- Concise data
- Poor outreach
- Low reimbursement rates
- Covers eligible conditions only (not comprehensive)
- Income for MI CHILD raised above 200%
- Lack of case-finding (expand partners)
- Prior authorization process too long
- Federal government unfunded mandates
- Lack of contact with registry
- No mental health coverage for CSHCS
- More collaborative efforts between service (local) programs
- Silos –separate funding programs, services
- Lack of funds for outreach
- Reduction in staff, resources
- Staff turnover: DHS, CSHCS
- Regional Center Meetings
- Excess funds returned (no carryforward)
- Provider, hospitals don't use expertise of local health departments

#### **Brainstorming Ideas**

- Use state dollars to draw down federal dollars. Advocacy.
- Support national health care with specific design for children and youth with special health care needs.
- Restructure local health departments for efficiencies in service delivery.
- PSAs
- Michigan Catastrophic Fund for CSHCS













